

## Medical Humanism and Empowerment Medicine

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### Definitions

Science is "any system of knowledge derived from observation, study and experimentation carried on in order to determine the nature or principles of what is being studied" (Webster's, 1955). Science can be a blessing and a curse. The discovery of radium through its radiological applications has revolutionized medicine: giving physicians the ability to look at internal organs, to quantify pathology, to track treatment outcomes, and to shrink malignancies. Yet, radium has also harbored death and destruction through atomic weaponry.

Humanism is "any system or way of thought or action that is concerned with the interests and ideals of people" (Webster's, 1955). As a cultural movement it stemmed from Greek and Latin literature and was one of the factors that stimulated the Renaissance.

Scientific humanism is the discipline of using systems of knowledge derived from observation in ways that optimize human interests and ideals. Though of potent potential, scientific knowledge is neutral. It is individuals and societies of individuals who choose whether knowledge is to be used for or against humanity. Scientific humanism is the good and the empowering part of science.

Medicine is "the science and art of diagnosing, treating, curing, and preventing disease, relieving pain, and preserving health" (Webster's, 1955). Medicine, as a scientific discipline, can both empower and defy life. Twentieth century medical advances have all but eliminated certain diseases, such as polio, and provided new organs to people who otherwise would have died. Yet, the Holocaust, which particularly devalued the lives of those with disabilities, illustrated the destructive potential of medical science at its worst.

Empowerment is a process of "giving power or authority to others as the president is empowered to veto legislation." Empowerment is also "giving ability to or enabling as science empowers man to control natural forces" (Webster's, 1955). Just as science empowers man to control natural forces, medicine, as a form of science, should empower people to control the direction of their own lives.

Empowerment medicine applies principals of scientific humanism to people. The health care professional, through his or her medical knowledge, becomes a vehicle to enhance the authority and ability of the patient, consumer, or client in ways that he or she becomes more in control of the direction and quality of his or her life. The knowledge required to empower spans traditional medicine, including prevention, diagnosis, and cure, but also includes a broader vision of experience in the contexts of the worlds in which people choose to live. By principles of empowerment, medical knowledge is returned to the patient in a way that enhances freedom, maximizes potential for achievement, and expands life choices. Rather than focussing narrowly on physical and mental processes, empowerment medicine embraces the natural environment and an individual's ability to access, control, and integrate oneself within it.

Empowerment medicine was first described by Nosek (1997) as it related to the gender-specific issues faced by women who experience disabilities. Dr. Nosek wrote that empowerment medicine can be delivered by "recognizing that women with disabilities are women first, and by offering them information about how disability effects maintenance of good health and functioning within their chosen lifestyles." Empowerment medicine recognizes that all people, no matter how severe their medical conditions or disabilities, are people first.

To practice empowerment medicine, the health professional uses scientific knowledge derived from many people to address the often idiosyncratic needs and responses of the single person.

## Disability Activists and Medicine

Disability rights advocates have severely criticized the medical model and some have been reluctant to establish formal relationships with providers in the health care industry (DeJong 1998, Independent Living Centers and Managed Care). The advocacy movement was established in the 1970s, largely in objection to the perceived paternalistic ways in which society, and particularly physicians, treated people with disabilities. The state of being considered abnormal, dependent, and in a position to accept orders from physicians without asking for explanations was seen as contributing to society's overall tendency to view people with disabilities as being passive, pathetic victims incapable of living independently in the community. The fundamental premise of the movement was that individuals with disabilities are handicapped primarily by barriers in the environment rather than by their own impairments. The removal of such architectural and socio-cultural barriers would allow many people with disabilities the freedom to function in society (DeJong 1992; Frieden, Richards, Cole, & Baily, 1979).

## Health Environmental Integration

Zola, as a founder of the Society for Disability Studies, noted that issues of health do not result solely from physical or mental impairments but rather from interactions between those impairments and practically every feature of the social, political, economic and physical environments (Zola, 1989). This is illustrated by the concept of health environmental integration (HEI). HEI is an ecological model that synthesizes many philosophical, sociological, and medical theories (Churchland, 1986; Cottingham, 1988; Goodman, 1991; Mauder, 1995; Nagel, 1993; Stineman, 1998). By this model, the individual seeks self-fulfillment through various physical actions and mental processes in response to and in association with the environment (Stineman, 1998). Physical states and actions influence mental states and vice versa. Mental and emotional self-concept, and indeed all actions and reactions in life, are colored by social expectations and cultural values. Just as the environment influences human potential or action, so do human actions influence natural environmental forces.

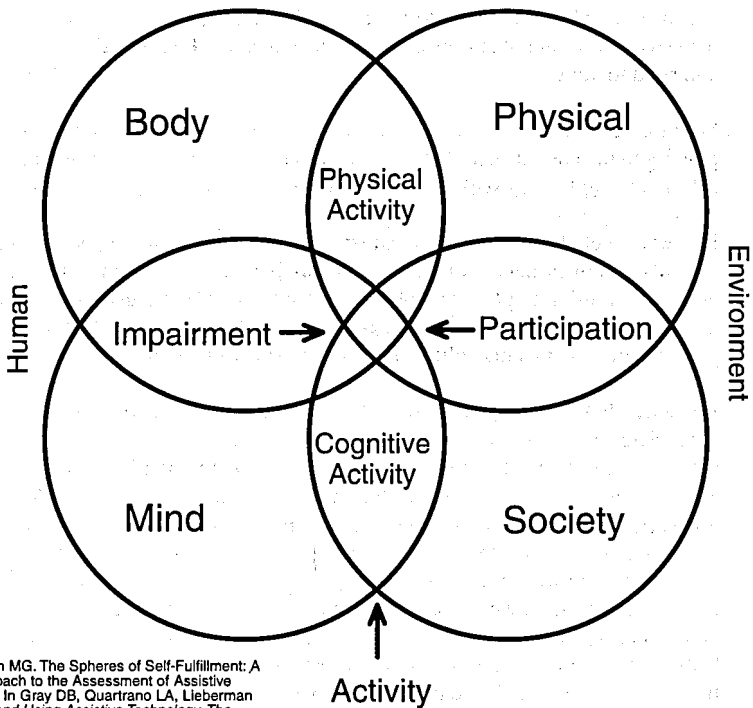
Illness and injury come from inside the body and also from environmental pathogens. If such conditions are not cured, they color long-term experiences, limit activity, and effect potential for participation in life functions. The World Health Organization expresses the experiential consequences of health conditions through its *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) (World Health Organization, 1980; World Health Organization, 1997). Impairment includes psychological, physiological, or anatomical abnormalities. Disability, or activity limitation, generally results from impairment and is defined as any restriction or lack that impairs ability to perform activities in a range considered normal. Handicap, or participation restriction, is defined as limitation in the performance of age-, gender-, or socially- or culturally- appropriate roles. These domains of experience can be placed within the spheres of HIE in a manner that shows how status of the person in conjunction with the environment determines the consequences of health conditions along the ICIDH dimensions of experience.

When a person with disabilities attempts to interact with the environment, he or she is often blocked by barriers and becomes displaced and marginalized. In contrast, a person who does not manifest disability more easily integrates self into the physical and social environmental spheres with complete access to built physical spaces and greater social opportunities. The environmental spheres become essential to understanding the needs of people with disabilities for whom the built environment, conditions of the terrain, social institutions, and cultural stereotypes, of no consequence to most people, become particular barriers to free participation.

The empowerment process attempts to rectify the displacement of persons from the environment, first, by maximally restoring function in the individual through traditional medical and rehabilitative practices, second, by attempting to expand access to the environment through assistive technology, and third, by removing barriers. Medicine traditionally prevents, diagnoses, and treats disease, relieves pain, and pursues health by studying and treating "abnormal states" of body and mind. To achieve the empowerment objective, the medical model must be expanded to include the physical and social environments. Empowerment becomes increasingly essential as symptoms of disability

become severe because when the patient loses control of body or mind, autonomy is easily lost. When autonomy is falsely believed to be lost, health care professionals or others may make decisions that the patient is capable of making. To maximize autonomy to the limit of the patient's mental capabilities,

# The Spheres of Health-Environmental Integration



Adopted from Stineman MG. The Spheres of Self-Fulfillment: A Multidimensional Approach to the Assessment of Assistive Technology Outcomes. In Gray DB, Quartrano LA, Lieberman ML (eds.), *Designing and Using Assistive Technology: The Human Perspective*. Baltimore, MD: Paul H. Brookes Publishing Co., 1998.

health professionals trained to focus on disease and dysfunction must simultaneously remain focused on retained health and innate abilities. Focus on health and abilities will be a shift for most physicians whose training emphasizes pathology and disability. Albeit that the pathology paradigm remains essential when managing the acute and emergently ill, once a life has been saved, full recovery depends on re-empowering the person to the point that he or she is able to reclaim responsibility for life.

With escalation of health-care costs, the time available for physicians to spend with the individual patient has become increasingly restricted, encouraging a narrow technical view of medical practice. Practice today is increasingly dominated by rules and guidelines intended to streamline care and to manage populations of people with similar medical conditions. While the meaningful classification of patients is essential, care must be taken to avoid using schemes to label or classify people in ways that encourage others to think that certain individuals have diminished value. While clinical guidelines can highlight best medical practices at the level of populations, the physician using them must recognize that the practice of medicine is by nature particular to the individual and is context

rich. Empowerment medicine uses classification schemes and guidelines as information tools within contexts of an individually focused practice. Empowerment asserts humanity before illness and disability. Knowledge is shared to the extent that the patient or client is able and chooses to know.

### **Principles of Scientific Humanism - an Open Letter to My Physician Colleagues**

1. The person who has disabilities is a person first. The body parts that are atypical are only single parts of the whole person.
2. Medical knowledge relevant to the person belongs to that person and is given freely and honestly in a manner that is sensitive to the patient or client's desires, ability to understand, and need to know.
3. When cure is impossible, the health professional applies care that returns maximal autonomy to the patient such that he or she has the greatest potential of reaffirming his or her selected lifestyle or of seeking an alternative.
4. Expressed belief in the abilities and productive potential of the patient can go a long way towards empowerment. This belief extends beyond disease and disabilities to focus on wellness, abilities, or personal potential. It could include interest in clay figures modeled by a spinal cord injured child or the sharing of a book written by a doctor who is blind with a young woman with a disability who wants to study medicine.
5. Be optimally knowledgeable and skilled, but operate beyond the role of a technician so as to appreciate the unique and personal experiences, challenges, and achievements made by those with impairment and disability. Recognize that particular disabilities and symptoms are of different consequences to different people. That recognition should shape therapeutic goals. At times, what one is trained to do may take on less importance than simple human kindnesses. Hospitals can be cold, lonely, and hostile places unless warmed by the hearts of those of us who work there.
6. Be prepared for and welcome expressions of unexpected beliefs, particularly when those beliefs conflict with scientific "truths." Unrecognized or unacknowledged differences in belief and experience may block meaningful interaction and communication between patients and physicians. There is scientific evidence that bronchodilators reduce mortality in asthma. This benefit is lost to the patient who chooses not to use bronchodilators because of the belief that all pharmaceutical agents are unnatural substances that block the body's natural recovery processes (Gilchrist & Engle, 1995). Encouraging personal expression respects intellectual autonomy of the patient and provides the physician with an opportunity to explain why treatments are being prescribed. It also provides an opportunity to rectify misunderstandings between the patient and physician.
7. Use knowledge about how the body works, not just to seek cure or palliation, but also in assisting people in their efforts to come up with life enhancing strategies. For example, provide knowledge about how joints work so that the patient with arthritis can learn how to spare the most involved joints and reduce pain and potential deformity.
8. Recognize that adaptive technology, including wheelchairs used when "walking fails" (Iezzoni, 1996), can liberate. Careful use of technology can reduce pain and provide the patient with that precious energy boost required to complete daily tasks. Physicians sometimes see the prescription of adaptive devices as "admitting" defeat, as evidence that they have "failed to arrest" disease. This attitude only serves to reinforce negative social stereo-

types and stigma against devices that can empower those who need them.

9. Guide the patient's selection of assistive technology but do not dictate. Your physician knowledge of physiology is a complement to the patient's self-knowledge and life goals.

Empowerment medicine is not intended to define a new medical specialty, but rather to be incorporated within all specialties as vision of the patient as "expert on his or her own life." Principles also extend beyond traditional practice venues. The knowledgeable and sensitive physician can join people who experience disabilities to influence the work of architects, policy analysts, and other individuals who shape our world or determine social values. Advocating for increased accessibility of the built environment and social institutions can go a long way toward empowering the lives of the people medicine and surgery can not cure.

Empowerment medicine provides practice principles for the treatment of all people whether able-bodied or not. Failure to follow those principles will disproportionately damage people with disabilities.

The principles of scientific humanism and empowerment medicine are evolving and should reflect the perceptions and needs of people who seek rather than provide care. Thus, the author invites and welcomes ongoing dialogue.

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